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ABSTRACT

The paper examines the possible role of siblings of handicapped children in helping or caretaking. A review of the literature is performed as a basis for proposing that there are circumstances in which intrinsically motivated, or altruistic, helping may be a more adaptive approach to coping with a handicapped brother or sister than other strategies, including enforced compliance to helping demands, indifference, or withdrawal. A model is presented which sets three kinds of antecedents as bases for voluntary adoption of a helper role within the family: demographic factors, personality variables, and situational factors. Research is reviewed on the predisposition to help, helping behavior, and mental health outcomes. It is concluded that there is evidence to support the position that voluntary helping may be used as a means for productive and successful coping with the stress of living with a handicapped sibling. (CL)

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COPING BY SIBLINGS OF THE HANDICAPPED: THE ROLE OF ALTRUISTIC HELPING

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THE ROLE OF ALTRUISTIC HELPING

While the literature on handicapped children has burgeoned in the past several decades, only in rare instances has the potential for the reciprocal influence of the child's handicap and the family been articulated (cf. Bandura, 1978; Masters et al, 1983; Minuchin et al, 1978). With the increased emphasis on school and family contextual factors attendant upon the passage of the Education for All Handicapped Children Act (P. L. 94-142), there has been an increased emphasis on the attitudes by teachers toward mainstreamed children (Hannah & Pliner, 1983), and families, especially mothers (Gabel et al, 1983; Seligman, 1983). On the other hand, although 80% of handicapped children have one or more siblings, the impact of the disability on the nonhandicapped sibling has rarely been systematically investigated (Simeonsson & McHale, 1981; McKeever, 1983).

The primary emphasis of investigators concerned with the effect of a handicapped child on the family has been on the child as a source of stress. Indeed, there is little doubt that stress is experienced as a consequence of having a handicapped family member (cf. Featherstone, 1980). On the other hand, there is evidence that a subset of siblings of persons with diverse handicapping conditions may experience the presence of a handicapped sibling as providing an opportunity for spontaneous helping (Midlarsky, 1973), a view that may be well-supported by attitudes and socialization practices existing within the family. There is also empirical support for the proposition that helping may not only benefit the recipient, but may also be associated with positive consequences for the benefactor (Fisher et al, 1981; Rakos & Schroeder, 1976).

Coping by Siblings of the Handicapped:

The Role of Altruistic Helping

ABSTRACT

This paper focuses on one of the most salient issues for siblings of the handicapped--their helping or caretaking behavior. A review of the literature provides a basis for proposing that there are circumstances in which intrinsically motivated, or altruistic helping may be a coping strategy which is potentially more adaptive than other alternatives--including enforced compliance to helping demands, indifference or withdrawal. A model is presented regarding the relationships among proposed antecedents and mental health outcomes for the sibling helper.

A Model of Successful Coping Through Helping

Theories of human development often focus almost exclusively on the causative role of factors beyond the individual's control. The role of constitutional variables (Beck & Rosenblith, 1972), social problems including exposure to poverty, divorce, unemployment, violence and prejudice (Dooley & Catalano, 1980; Eron & Peterson, 1982; Finkelhor, 1979; Gruber, 1978; Tizard & Hodges, 1978), and factors within the family including child-rearing attitudes and behaviors (Barsch, 1968; Baumrind, 1971; Hoffman, 1975), family systems and their concomitant social structures (e.g., Bowen, 1976; Jackson, 1970), and others, are often perceived as determining the outcomes of the developmental process. Missing from certain of these treatments of child development is consideration of the child as agent who has the capacity to act upon his or her environment, as well as being influenced by it (Bell, 1977, 1979; Parke, 1978).

Unilaterally deterministic approaches to development are essentially "tabula rasa" theories, whereby the developing organism is a relatively passive recipient of influences upon him or her. Yet, as Bell points out, in presenting the tabula rasa concept we often forget that John Locke "only intended it to mean that the infant does not start life with preformed ideas, such as that of original sin (Bell, 1979, p. 823)." Congenital differences may indeed be influential. For example, there is evidence for an intrinsic motive to be an active initiator of behavioral sequences, primarily as a means for enhancing or exercising one's own competence, effectance, or mastery (White, 1959, 1963; Fiske & Maddi, 1961; Hunt, 1963; Kavanau, 1967). Thus, as Harper discovered, among mammals it is the extreme interest by the young in adventurous explorations which leads to the adaptive expansion of the group to new territories. Among human beings, some of the most creative contributions are made by the young, who often bring

vitality, excitement and change to families and to the broader civilization. Contributions by the young person to the welfare of the family, while relatively unexplored, is potentially of both great theoretical and practical significance.

Congruent with the growing recognition of the impact of the child's effects on his or her environment, there has been a modicum of support for the notion that human functioning may be, at least to some extent, independent of life circumstances. Consider the case of eleven year old Sarah who is doing very well despite the fact that everything seems to be going against her. Her parents are separated, her father is in prison, she has two handicapped siblings--one mentally retarded and one dying from sickle cell anemia--her mother works long hours as janitress in a factory, and the family is on welfare. Yet, for those whose goal has been primarily to comprehend adjustment difficulties and serious psychopathology, the determinants of children's strategies for coping with difficult life situations, which may modify the effects of those situations, has been largely overlooked. As Murphy pointed out,

> It is something of a paradox that a nation which has exulted in rapid expansion and its scientific-technological achievements should have developed in its studies of childhood so vast a "Problem Literature." A literature often expressing adjustment difficulties, social failures, blocked potentialities, and defeat . . . . In applying clinical ways of thinking out of experiences with broken adults, we were slow to see how the language of adequacy to meet life's challenges could become the subject matter of psychological science . . . . We know that there are devices for correcting, bypassing, or overcoming threats, but for the most part, these have not been directly studied (Murphy, 1962, p. 2).

Research by a small band of investigators has recently begun to specifically study those "super-kids" or "invulnerables" who demonstrate amazing strength and resilience even in the face of circumstances which would seem to make them prime candidates for psychopathology (Anthony & Koupernik, 1974; Garmezy, 1976; Garmezy & Rutter, in press). These writers do not deny that problems such as poverty, family instability and the like may constitute excessive burdens, but rather that under certain circumstances, competence and strength may develop even

in the face of severe deprivation and obvious hardship. Indeed, it appears that what may be an inordinate stress for one individual, may serve as a challenge, or spur to creative coping by another.

A coping strategy which appears to be an active means for enhancing a wide range of competencies, obtaining a sense of mastery and alleviating personal distress, is the provision of help to others (cf. Midlarsky, 1968, 1984; Midlarsky & Kahana, 1981a, b, 1983). In regard to the role of helping in skill acquision, the literature on peer-tutoring indicates that low-achieving children placed in the role of tutor achieved considerable improvements in their own reading level (Allen & Feldman, 1976). Within families, having a sibling whom one can help is a significant boost to one's intellectual development. As Robert Zajonc writes, "Assistant-parenthood gives older children much experience in solving intellectual problems that their younger siblings want solved....It is better to have a younger sibling you can show the world than an older one who shows it off to you (Zajonc, 1975)."

The literature also provides numerous instances wherein being called upon to care for one's siblings may, under certain circumstances alleviate personal distress and lead to the sense of competence and of compassion (cf. Bank & Kahn, 1982; Grossman, 1972; Midlarsky, 1984; Seligman, 1983). In contrast to the prediction by equity theory, that if either individual in a relationship gives more than s/he gets both become distressed (Adams, 1963, 1965; Walster, Berscheid & Walster, 1973, 1978), research indicates that if anyone suffers, it is the recipient who suffers most (Castro, 1974; Gross & Latane, 1974; Clark, Gotay & Mills, 1974). Helpers often feel good about their actions even when they have given more than they received (Rachman, 1978; Midlarsky & Kahana, 1982; Worchel, 1984).

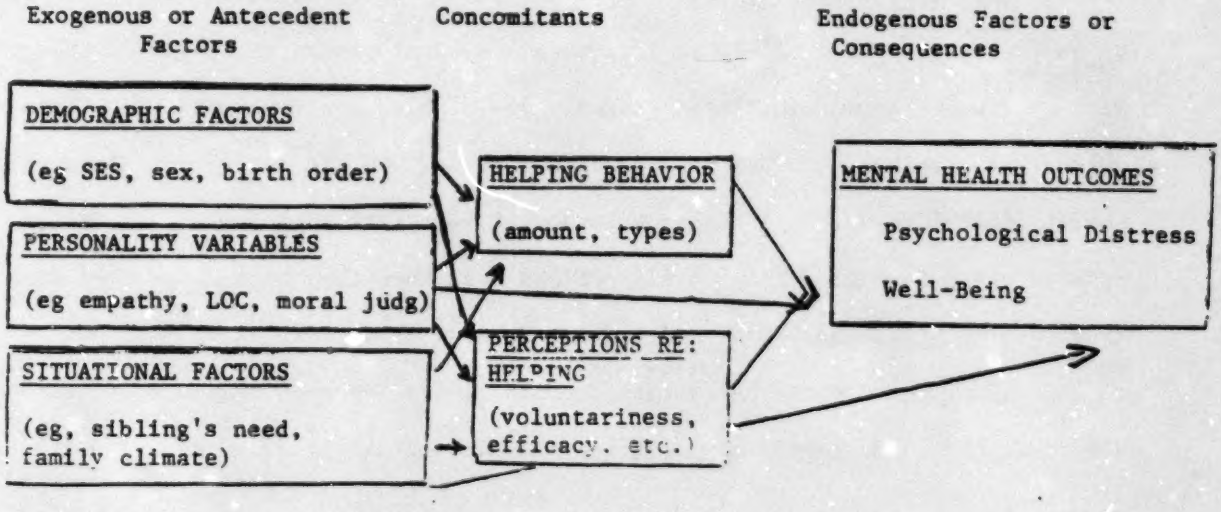
It is proposed here that within certain limits, by providing help to one's siblings, the young person may derive critical benefits by alleviating emotional

distress and curtailing the sense of helplessness, that may result from being a victim of stressful circumstances--such as having a handicapped sibling. In addition to the knowledge that one has made an important and worthwhile contribution, effective helping may reduce the probability of extreme distress in siblings of the handicapped, and augment the sense of connectedness to others, and the sense of well-being.

In this model of successful coping through helping, we propose that the relatively voluntary adoption of a helper role within the family may be based on three kinds of antecedents: personal antecedents (including sociodemographic factors and motives) and situational variables (e.g., the cost of helping). It is proposed that siblings of the handicapped who engage in intrinsically motivated helping experience lesser degrees of depression and anxiety, and higher levels of self-esteem and psychological well-being, than do siblings of the handicapped who do not engage in helping. Altruistically motivated, moderate levels of helping are expected to serve as an active form of coping associated with lower probabilities of emotional problems for siblings of the handicapped. The model is outlined in Figure 1

Figure 1

Model of Successful Coping Through Helping



As indicated in Figure 1, several demographic, motivational and situational factors are anticipated to impact both on helping and on mental health outcomes. The impact of these variables--e.g., sibling's impairment, parental expectations and family climate--on mental health is mediated by the amount and type of helping and by perceptions about the helping (e.g., its voluntariness, importance, and its efficacy). It is our view that siblings perceiving themselves as voluntarily providing moderate amounts of help, particularly when they consider helping both important and efficacious, are likely to experience lower amounts of psychological distress and greater psychological well-being, than siblings with different experiences within the family. Our expectation of positive adjustment under certain circumstances is at variance with positions which emphasize the high probability of adverse emotional sequelae for siblings (Trevino, 1979; Poznanski, 1969; Weitzman & Messenger, 1981).

Empirical Perspectives

The Predisposition to Help

In contrast to an earlier emphasis on anti-social behaviors and aggressive motives, in recent years there has been a substantial increase in systematic attention to altruistic motives, and predispositions to help (Midlarsky, 1968, 1984; Midlarsky & Hannah, in press; Eisenberg, 1983; Rushton, 1980; Staub, 1978). Observers of social and interpersonal phenomena have noted that while instances of cruelty and indifference abound and are frequently the subjects of mass media coverage, acts of kindness, consideration and self-sacrifice are apparent as well. Furthermore, research on the antecedents of helping has determined diverse situations in which there appear to be intrinsic motives to help the other individual.

According to certain instinct theorists, human beings have a "killer" instinct (Hobbes, 1958), or a Cain tendency (Ardrey, 1962). Just as evidence and theory have been marshalled to support a biological basis for human aggression,

the literature of psychobiology is replete with examples of altruism both within the human species and in subhuman species. Darwin (1871) provided numerous examples of altruism in the animal world--the defense of cows and calves by bull bisons, warnings of coming predators by rabbits, sheep and monkeys, caretaking and grooming by chimps--all of which are costly in terms of time spent or danger incurred by the altruistic animal. More recent evidence for animal altruism, including such categories as cooperative defense, food sharing and rescue behavior, has been presented by E. O. Wilson (1975) in his volume, Sociobiology. The predominant emphasis in the literature on altruism within subhuman families has been on help by parents toward offspring (cf. Wright, 1971; Wilson, 1975; Rushton, 1980). However, Jane Goodall (1968, 1971) wrote of cases of chimpanzees who upon being orphaned, were adopted--altruistically--by adult siblings.

Evidence from psychological studies suggests that even very young children display predispositions to respond with empathy, care and kindness to distresses and problems of others (Zahn-Waxler, Radke-Yarrow & King, 1983), and that the capacity and motivation for prosocial behavior appear at between one and one-and-a-half years of age (Yarrow, Scott, & Waxler, 1973; Hoffman, 1975; Murphy, 1937). Studies of personality and character have also found that there appear to be generalized dispositions to display cross-situational altruism (cf. Midlarsky & Suda, 1978). Hence, preschool children who are cooperative, are also nurturant toward others (Friedrich & Stein, 1973). Among the fifth to eighth graders studied by Dlugokinski & Firestone (1974), children viewed as kind by their peers were also likely to be generous with their money, and had some notion of the concept of kindness. Furthermore, results obtained by Baumrind (1971) indicated that sympathetic preschoolers were also likely to be thoughtful, nurturant and less insulting to their peers than were those children who exhibited less sympathy.

The predisposition to help observed among unrelated peers has also been noted among siblings. Bank and Kahn (1982) refer to numerous instances in which siblings are motivated to exhibit unilateral loyalty and caretaking. Writing from a psychoanalytic perspective, Petty (1953) indicated that even in situations in which there may be intense rivalry, wherein siblings compete for status, love and attention, it is possible to observe indications of the motive to rescue one's siblings.

Motives or predispositions to help are particularly notable in extreme situations, particularly those which threaten survival--including natural disasters, concentration camps, and combat situations (e.g. Bettelheim, 1960; Torrance, 1965; Wallace, 1956). While membership in a family with a handicapped child is most certainly not comparable to such situations in magnitude or intensity, the stress associated with disabilities appears to share some elements in common with extreme stressors. Among the common elements are the facts that these stressors are unexpected, brought on by factors beyond one's control, and traumatic. A volume by Des Pres (1976) which is replete with observations and intuitions about extreme situations outlines 14 psychosocial elements, several of which may be relevant here. For example, the extreme situation--like sibship with a handicapped child--is not a discrete event with a clear-cut beginning, middle and predictable end--but rather a state of existence, often without expectation of future alleviation. In such situations, nobody ever survives without help. Helping behavior is both greatly needed, and frequently observed. Investigators of interpersonal behavior in natural disasters (e.g., Wallace, 1956) and among concentration camp inmates (Des Pres, 1976) have noted that indeed, in these contexts, helping and giving appeared to be major forms of behavior. This, in turn, has been viewed as evidence that at least among those exposed to certain adverse situations, "the need to help is as basic as the need for help (Garfield, 1979b, p. 3)."

We anticipate that critical antecedents of helping will fall into the following categories--sociodemographics (e.g. sex, SES and birth order), motivational factors, and situational factors. However, it may be noted that in addition to the generalization that individuals in traumatic situations may be predisposed to help, the literature on helping indicates that children may be more likely to learn empathy, social responsibility, compassion and other motivational antecedents of altruistic helping precisely as a result of their interactions with others who may need their help (cf. Berndt, 1982; Sullivan, 1953). For those siblings who opt to help the handicapped family member, particularly if they are motivated at least in part by such intrinsic factors as compassion and locus of control, help given may benefit the normal sibling by providing a sense of self-esteem and well-being. At the same time, helping may mitigate anxiety, the sense of social isolation and depression born of a sense of helplessness in the face of unconquered adversity (cf. Seligman, 1975; Peterson & Seligman, 1983; Janoff-Bulman & Frieze, 1983). Hence, helping that is predisposed, at least in part, by exposure to a disabled sibling may mitigate the normal siblings' negative emotional reactions, and enhance their sense of well-being and connectedness to others (Des Pres, 1976).

Helping Behavior

In the literature on altruism and helping behavior, there has been little emphasis on the systematic investigation of helping within the family. However, in the few investigations which have been conducted on sibling interactions, helping behavior has often been observed to occur, despite theoretical orientations and popularized accounts of sibling interaction which emphasize the "naturalness" and primacy of sibling rivalry (Levy, 1937; White, 1975). For example, Bryant and Crockenberg (1980) observed that helpfulness occurs among elementary school age siblings, with the older more often helping the younger child. Cicirelli (1976) found a high level of empathy expressed among normal siblings, and Dunn and Kendrick (1979) observed interactions reflecting empathy and altruism, even among

siblings of a very young age. Helping acts included help given to a frustrated sibling to overcome the obstacle, and offering material objects to a sibling exhibiting distress. Pepler, Corter and Abramovitch (1982), observing siblings in naturalistic settings, found that while aggressive interchanges did occur, altruistic interchanges predominated.

Generalizing about children's behavior in six cultures, Whiting and Edwards (1973) stated that children most frequently exhibit helping behavior, supportiveness and sociability when interacting with infant siblings. Interactions of children with younger siblings revealed numerous instances of nurturant behavior, including offering or sharing material goods, provision of attention, help, comfort and physical care (Edwards & Whiting, 1980). The amounts of altruism among siblings tended to vary widely with diverse amounts of time spent and degrees of responsibility attributed by parents for caretaking and nurturance. Hence, Whiting and Whiting (1973) noted that within achievement-oriented, competitive and highly industrialized societies like the United States, children are less likely to be given resposibility for child care within the family, and hence are less likely to exhibit altruism.

In a study on the development of specialized roles within the family, Bossard and Boll (1955) discovered eight types of role adopted by children from families with six or more siblings. These roles included the responsible role (parental substitute), popular and well-liked (charm is emphasized), socially ambitious, studious, self-centered, isolate, irresponsible, unwell, and unliked. Even in families with no handicapped family member, then, a child within the family may accept considerable responsibility in order to alleviate demands upon the parents.

Significantly, the literature on altruism and helping often includes suggestions about ways to model helping behavior, or to attribute responsibility to children in order to teach them what is considered a very important social behavior--

prosocial/moral action (Staub, 1978; Rushton, 1980). Yet, the literatures of social and developmental psychology rarely indicate any recognition of naturally-occurring situations within U. S. society in which helping and caretaking by siblings are a daily occurrence, i.e., families in which there is a handicapped child. Indeed, the recurrent emphasis on helping relationships within such families (cf. Seligman, 1983) may occur because unlike the situation in the U. S. population at large (Whiting & Whiting, 1973), opportunities for helping and attributions of responsibility to well siblings may be a relatively frequent occurrence, with the preponderance of siblings involved in helping and caretaking (Cleveland & Miller, 1977; Hannah & Midlarsky, 1985; Holt, 1958; McAndrew, 1976; Travis, 1976). For example, within the parental home, McAndrew (1976) reports that 75% of the siblings of children with cerebral palsy or spina bifida, who were themselves over the age of seven, were expected to provide help. Responsibilities included dressing, toileting, feeding, supervising, and occupying the siblings, as well as helping put on the braces. Similarly all of the teenage participants in the research by Graliker, Fishler and Koch (1962) were asked to assume some responsibility for a sibling with Down's syndrome.

In families with handicapped children, responsibilities and caretaking by siblings occur not only in the present, but are projected into the future, as well. As Featherstone (1980) and Klein (1972) point out, brothers and sisters often believe that when their parents are no longer alive, they will have to assume responsibility for their handicapped sibling. As one woman (Zatlow, 1982, p. 31) wrote:

> It is inevitable that one day I will lose my parents. I will inherit whatever constitutes their estates, be it money or debts, but their most important legacy will be in the form of my autistic brother. As his future guardian, I will acquire and accept full responsibility for Douglas.

In most of the research conducted on siblings of the handicapped (e.g., McAndrew, 1976; Graliker, Fishler & Koch, 1962), comparison groups of children with

normal siblings were not included, so that it is difficult to determine whether or not responsibilities exceeded those typically given to siblings. However, one study indicates that such may be the case. Swirean (1976) compared siblings of hearing impaired or normal four-year-olds on three indices of responsibility--child care responsibilities, general home responsibilities, and extent of social responsibility. Results indicated that siblings of the hearing impaired preschoolers had significantly greater child care and general home responsibilities, and lower social responsibility scores, than siblings of the normal preschoolers.

In sum, very few investigations have contrasted the behavior of siblings within families with a handicapped child with siblings of nonhandicapped persons. However, the few investigations that have been conducted point to a higher degree of helping in siblings of the handicapped, and further indicate that there may well be individual differences in the adoption of a helping role (e.g., Bossard & Boll, 1955; Carver & Carver, 1972).

Mental Health Outcomes

Research papers on altruism and helping have often cited positive consequences experienced by the helper. Increases are noted in knowledge and other competencies for peer tutors, and for older siblings who nurture and teach their younger siblings (Allen & Feldman, 1976; Cicirelli, 1976; Zajonc, 1975). Social skills obtained through involvement in helping interactions-within one's own social of familial doman may also lead to enhanced bonding and increased social integration within the family or the wider community (Midlarsky & Kahana, 1981a, b, 1982; Zahn-Waxler, Iannotti & Chapman, 1982). The meeting of adversity through the kind of active coping represented by intrinsically-motivated helping may be a way to avoid passivity, "learned helplessness," and its concomitant, depression. Active coping and striving toward adaptive mastery and competence (Hartman, Kris & Lowenstein, 1949; Erikson, 1950), have also been found to result in diverse

positive outcomes for the helper (e.g., Gal & Lazarus, 1975).

Altruistic behavior is, by definition, a form of behavior intended to help others and not expected to bring extrinsic rewards (Midlarsky, 1968, 1973; Midlarsky & Suda, 1978). On the other hand, intrinsic rewards may result. Helping others may lead--however unintentionally--to the development and maintenance of satisfying emotional and social bonds. There is also some evidence that helping may be related to a sense of well-being, and even to physical survival (Eibl-Eibesfeldt, 1972; Havighurst, 1961; Midlarsky, 1984). Furthermore, studies of the survivors of natural and man-made disasters indicate that the individual responsible for others appears to maintain a higher level of physical and psychological integrity than one who is protected and helped (e.g., Rachman, 1978; Nadler & Ran-Venaki, 1979). For example, Rachman noted that individuals who are most active in a socially responsible way during stressful times appear to experience less fear and anxiety than those who are less active on behalf of others.

In regard to siblings of the handicapped, Grossman found that normal children who took a parental stance toward a retarded brother or sister discovered that they had indeed found an acceptable and comfortable way to relate. Indeed, helping and teaching the handicapped sibling was reported to give them some sense of mastery, and to reduce their anxiety. Those individuals taking less responsibility --usually male siblings--also seemed to suffer more discomfort, including anxiety and extreme embarrassment. Bank and Kahn (1982) noted that in at least some cases, siblings of impaired individuals coped by helping, and concomitantly assuming an identity as a competent and masterful individual. They further pointed out that the helping role may extend into adult life; it appears, in their view, that many mental health professionals have impaired siblings.

In contrast to the optimism expressed in studies of helping in regard to outcomes for the helper in a handful of studies (e.g. Barsch, 1968; Graliker,

Fishler & Koch, 1962; Grossman, 1972), the literature on siblings of the handicapped has often been pessimistic, and focused on adverse emotional sequelae for these individuals. Furthermore, the attribution has often been made that involvement in caretaking and other helping activities on behalf of the impaired sibling may be an important source of later emotional difficulties. Notable in these treatments is the recurrent theme of responsibility, often onerous, not chosen by the individual but thrust upon him or her--especially in families in the lower socioeconomic classes. Siblings experiencing "imposed caretaking" apparently have most frequently been females (cf. Seligman, 1983), a fact of which feminists have increasingly been taking note. In Miller's words,

> In our culture, "serving others" is for losers, it is low-level stuff. Yet, serving others is a basic principle around which women's lives are organized, it is far from such for men (Miller, 1976, p. 60).

Serving as a challenge to Miller's statement is the observation, particularly in times of family stress, that the role of voluntary giver of help strengthens the family member's view of self, reducing anxiety about the outcomes for a loved one, and mitigating depression born of helplessness. Indeed, such actions seem to convey to all involved that the helper is an effective participant in the family group, even under conditions of adversity (cf. Caplan, 1982).

The frequent emphasis on adverse emotional sequelae for siblings of the handicapped (e.g. Poznanski, 1969; San Martino & Newman, 1974; Trevino, 1979) and the concomitant assumption that reports of courageous and optimistic responses to handicap bespeak denial of reality, is customary in the medical model (Wolinsky, 1980; Brickman et al, 1982). In the medical model, the individual is seen neither as responsible for the problem, nor for the solution--which is the charge of expert helpers, including therapists. Congruent with this model, siblings of the handicapped are seen as recipients of a problem not of their making. A solution to the problem of having a sibling who is essentially unsatisfying,

a difficult family life, and for being "saddled" with responsibility would lie in therapy designed to help discharge resulting aggressive feelings and the sense of deprivation. Conversely, in the model proposed here, siblings of the handicapped are seen as having the potential for being active agents, whose attempts at mastery through helping may be an important source of their well being.

Conclusion

In sum, this paper presents evidence in support of the position that voluntary helping may be used as a means for productive and successful coping with the stress of living with a handicapped sibling. In contrast to the view that adverse emotional sequelae are necessary consequences, which may be averted only by protection from caretaking responsibilities, we propose that such helping behavior may, under certain conditions, be associated with positive outcomes. Methodologically sound investigations of the conditions under which helping may have positive consequences, are expected to contribute to our theoretical understanding of the role of helping as a form of active mastery. The practical consequences of such research include the development of clinical intervention strategies designed to prevent or ameliorate disruption and distress among families of handicapped children.

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